

FULL COUNCIL MEETING

March 15, 2006

RADISSON AIRPORT HOTEL

Present: Frank Maher, Jeanne D'Agostino (Easter Seals RI), Lois Simpson (aide, Zambarano), Frank Beazley, Cheryl Gilmour (aide, Zambarano), Millie Feeney, Ina Woolman, Helen Sebesta, Leif Sebesta, Kathryn O'Connor, Katie Lowe, Claudia Lowe, John Susa, Mark Susa, Andre Thibeault, Tom Thibeault, Charles Zawacki, Stasia Zawacki, Alton Stuckey, Kathy Leonard, Dan Caley, Renee Doran, Megan Raynolds, Liz Cummisky, Susan Roush, Kathleen Samways, Chris Singleton, Marie Citrone, Gail Votolato, Mary Okero, Anne Rule, Raymond Bandusky, James deBoer, Denise Desmaras (aide, Leif), Lesa Andreasen

I. APPROVE MINUTES

Chris welcomed guests, and all meeting attendees introduced themselves. A motion to approve the minutes of the January 18, 2006 Council Meeting was made by Kathy, seconded by Frank Beazley, and was carried.

II. PANEL DISCUSSION

Lesa Andreassen was introduced to all. She facilitated a discussion on some items listed in the “Agenda For Full Participation” document. Lesa indicated the importance to bear witness to what is going on – what lives are like, and what people’s wishes are. The panel consisted of the following members: sons/daughters: Mark Susa, Katie Lowe, Leif Sebesta, Alton Stuckey, Tom Thibeault, Charlie Zawacki; parents/representatives: John Susa, Claudia Lowe, Helen Sebesta, Kathy Leonard, Andre Thibeault and Stasia Zawacki.

John Susa made a brief presentation about the Summit at the Alliance for Full Participation, and its purpose.

Introduced to all were the following: Mark Susa, Katie Lowe, Leif Sebesta, Alton Stuckey, Tom Thibeault, and Charlie Zawacki. They focused on the following questions: What is a regular week like? Are you happy with this? Do you wish to do other things?

Also introduced were John Susa, Claudia Lowe, Helen Sebesta, Andre Thibeault, Stasia Zawacki and Kathy Leonard (responding for Iraida Williams). They focused on the following questions: What impact does funding for your son or daughter have on the family? If you had more control over the money, what would you do?

Alton indicated that he is working at Training Thru Placement on Tuesdays and Thursdays doing piecework. He told Council members

that he has held this position since October 2005. He receives a \$20 paycheck every two weeks. Alton also participates in the Healthy Lifestyles Service Learning program, he volunteers at UCP and the Birch Vocational School. He goes to church on Sunday. He indicated that overall he is happy with what he is doing, but would like more volunteer work or perhaps have a job relating to art.

Charlie stated that he is working at a credit union in Central Falls five-days per week from 10:00 A.M. – 12:30 P.M. as a mail clerk/project assistant. He stated that he receives services from the Arc of Blackstone Valley. Charlie indicated that he would like to have his own apartment. He stated that he is very grateful to have his job, and that life is pretty good.

Leif told Council members that he works at Walmart as a paid greeter, and also volunteers at the VA Hospital on Tuesdays and Fridays working with medical records and at the information desk. He stated that he is happy with his job at WalMart because he gets paid. He indicated that he would like to do more at the VA Hospital. Leif also stated that he may be going bowling on Wednesday nights with Tom. He also swims at the McDermott pool.

Tom is 23 years old. He is involved with the Bridges Program, where he does art/recreational work, as well as library and office work. Tom also attends the Greenleaf Center, where he receives massages and spas. On Wednesday, Tom sells cards at the East Bay Manor; and on

Thursdays, he attends the Meeting Street School gym. He volunteers at the VA Hospital on Fridays. On Wednesday evenings, he goes bowling, and “hangs out” on the weekends. Tom indicated that he is happy.

Mark works Monday thru Friday training people with development disabilities on how to use the RIPTA bus. He indicated that this is a paid position. Mark told us that he learned how to ski in the White Mountains this past winter. He enjoys reading books on his free time.

Mark recently moved into his own apartment, and is very happy. On Wednesdays and Saturdays Mark goes to the gym and then does his shopping.

Katie works at the Cornerstone Adult Day Care on Tuesdays and Thursdays. She volunteers doing arts and crafts, and also passes lunches out. On Fridays, she attends an Advocates in Action leadership class. She enjoys going to her girlfriend’s house, and also attends a yoga class at Perspectives on Fridays and Mondays. On the weekends, Katie enjoys going to the movies. She indicated that she would like to work at a pre-school with children.

Helen indicated that Leif is presently living in a home behind hers that the family purchased. She is directing all staffing for Leif. Although she stated that it was a lot of work, it allows each to live independently. She indicated that if she was to obtain more money from the state, she would use some for purchasing a van for

transportation, as the RIDE van is not always reliable.

Claudia stated that if she had more control, she would make sure that staff was more dependable. She indicated that since September she has had staffing problems, and at one time Katie was left alone at home. She stated that she would like to try and find more community activities for Katie during the week.

John told Council members that life is good. He stated that the state provides adequate funding. He is able to obtain 55 hrs. per week in assistance, but stated that he has never used that much. If there were more money he indicated that he would use it so that Mark could be taken to more cultural events, etc. He indicated that Mark enjoys these types of activities and saves his social security money so that he can attend them.

Andre stated that when Tom transitioned from Meeting Street to the adult service program, it was an awakening. His wife had to give up her job in order to plan for Tom's daily activities. He indicated that the RIDE bus is not always available, and for this reason they use their own van. He stated that right now he feels "fortunate." Andre expressed concern about cuts in the day program, but is now relieved that they won't happen. He indicated that they have stayed in Rhode Island for the support they receive. In general he is pleased.

Stasia indicated that Charlie lives a full life, although he hasn't been

approved for funding for an apartment yet. She stated that she has no way of knowing if he will ever get funding, and this has made planning for the future difficult. Charlie has a goal of having his own apartment by the time he is 30. Stasia noted that impact of funding on family life, stating that the children were primarily dependent on their parents. She also indicated that there were transportation issues. Charlie attends a recreation program through Options, which Stasia is pleased with.

Kathy spoke for Iraida, Alton's guardian. She stated that there was not enough money to cover monthly expenditures, and that Alton must be budgeted into their own budget. She indicated that Alton would love to do more fun activities, and possibly attend a RISD class.

After the presentations, a general conversation took place. The following was stated:

- Charlie stated he had moving out in his ISP all along and was told that he was on hold; although only recently he was put on a waiting list. He indicated that it did not look like there would be enough funding for him to get an apartment.
- Helen encouraged Stasia and Charlie to be innovative and not rely on just DDD funding.
- John indicated that self-directed help through Options allows them

to have more money. Mark's apartment is a five-minute walk from their house. He stated that they waited a long time for the opening. John told Council members that money goes first to group homes and last to individuals living at home with their family.

III. OTHER

Helen told Council members that she spoke with the Governor today for approximately 45 minutes. She indicated that she and Marie will meet with Governor Carcieri about Money Follows the Person.

The meeting adjourned at approximately 6:00 P.M.

Respectfully submitted,

Mary Okero

MO/gv